
Gender and Home-Based Care for HIV/AIDS and TB Patients in Rural and Urban Zimbabwe

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Résumé

Cet article étudie la charge genrée des soins à domicile dans les ménages affectés par la tuberculose et le VIH/sida en zones rurales et urbaines du Zimbabwe. Sur la base de recherches menées à Bulawayo et Tshelanyamba en 2005-06, nous avons demandé aux soignants comment leurs vies, gagne-pain et charges de travail ont été affectés par la prestation de soins. La plupart des soignantes (qui sont tous des femmes) étaient préoccupées par la sécurité alimentaire et le coût des soins de santé, y compris le transport. Les gagne-pain tels que l'agriculture et le commerce informel ont été interrompus lorsque les patients étaient très malades, mais de nombreuses femmes ont été contraintes de reprendre leur travail en désespoir de cause. Des époux malades en phase terminale qui sont revenus après une longue absence afin d'être pris en charge ont été mal accueillis, notamment par les enfants. Les services de soutien des soins communautaires ont été particulièrement actifs en zones rurales. Les soignantes ont déclaré une augmentation de leur foi et de leur confiance en soi pour leur rôle de leadership assumé. Dans de nombreux foyers, les rôles de genre ont fluctué alors que les hommes et les garçons ont assumé davantage de responsabilités domestiques afin de soutenir les soignantes épuisées. Les ménages ayant accès au soutien de la famille élargie, ou ayant les ressources nécessaires pour embaucher de l'aide, ont été les plus résilients. Les soignants étaient vulnérables physiquement et émotionnellement; la plupart avaient désespérément besoin de formation, d'équipement et des soutiens spirituels et psychologiques nécessaires pour affronter la charge et le traumatisme de la prestation de soins.

Abstract

This article explores the gendered burden of care in TB and HIV/AIDS affected households in rural and urban Zimbabwe. Based on 2005-06 research conducted in Bulawayo and Tshelanyamba, we asked carers how caregiving has affected their lives, livelihoods and workloads. Most carers

(all of whom are women) were worried about food security and the cost of health care, including transport. Livelihoods such as farming and informal trade were interrupted when patients were quite ill, but many women were forced to resume their work out of desperation. Long absent, terminally ill husbands who returned home to be cared for were often resented, particularly by children. Community care support groups were especially strong in the rural areas. Carers reported increased levels of faith and self-confidence for their assumed leadership roles. In many households, gendered roles were in flux as men and boys assumed greater domestic responsibility to support exhausted carers. Households with access to extended family support, or who had the resources to hire help, were the most resilient. Carers were vulnerable physically and emotionally; most were desperate for training, proper equipment and the types of spiritual and psychological support needed to deal with the burden and trauma of caring.

Introduction

Sub-Saharan Africa has been devastated by the HIV/AIDS pandemic; even though the subcontinent has just over ten percent of the world's population, it is home to sixty-eight percent of all people living with HIV, currently numbering 22.5 million people. In 2009, there were an estimated 1.8 million new infections while 1.3 million adults and children died of AIDS (UNAIDS 2010). The epidemic has been particularly devastating to women and girls, who make up a large proportion of the infected population. Women's greater physiological susceptibility to infection, combined with multiple concurrent sexual partners, has proven a lethal combination. In South Africa, for example, Mark Hunter (2002) discovered that many poor women in the squatter settlements of Durban sold sex to wealthier, often HIV infected, older men whose sexual practices endangered them as well as their other partners, including their wives.

The social implications of Africa's HIV/AIDS pandemic are devastating and are only just emerging. Africa now has more than eleven million orphans, forty percent of all children eligible for elementary school are not in school because they are providing care for sick relatives, and in 2001 more than one million children lost their teachers to AIDS (CBC TV, "Canada and AIDS," interview with Stephen Lewis, 18 June 2002). The social, psychological and

economic impacts for both poor rural and urban households are catastrophic, with loss of productive labour and income. Savings and assets are used to meet health care and funeral costs, children are removed from school to provide care or to earn money, and there is a reduction in nutrition levels (Grant and Palmiere 2003; Lowenson and Whiteside 1997). As with infection rates, women and girls bear a disproportionate burden within the HIV/AIDS context as they struggle to provide care for the sick, earn extra income through low-paying informal activities (often selling sexual services that increase the possibility of infection), borrow from relatives, struggle to grow food, look after the extended family — including AIDS orphans — and provide unpaid community care support (Grant and Palmiere 2003; Brouwer *et al.* 2000; Gilbert and Walker 2002; Levine 1996; “Does Care Have a Price in Africa?”). Girls are more likely to be pulled out of school before boys to help with household and care duties, earn money, and save on school expenses.

Women and girls are seen as the “natural” carers, and consequently are expected to carry the burden of caregiving without a complaint. Although a few studies have examined community and household responses to HIV/AIDS (Barnett and Blaikie 1992; Mutangadura, Mukurazita and Jackson 1999; Altman 1994; Palmiere and Grant 2001; Grant and Palmiere 2003), little has been said about the gendered burden of caregiving in HIV/AIDS households and its impact on gendered practices and relations or on community and family life. This article explores these questions in both rural and urban Zimbabwe, in the belief that a deep understanding of gender and home-based caregiving to HIV/AIDS and TB patients requires an in-depth analysis of specific familial, institutional and community sites. The article draws on data from a study investigating medical and gendered social dimensions of HIV/AIDS care at household and community levels in Bulawayo, Zimbabwe and its hinterland.

THE ZIMBABWEAN CONTEXT

The AIDS pandemic has continued to escalate within Zimbabwe, fuelled directly (and indirectly) by the economic and political crisis of the last fifteen years. In 1997, the World Health Organization (WHO) indicated that 25.84 percent of Zimbabweans were infected

with HIV, and this figure increased to 33.7 percent by 2002 — the third highest in the world. Nationally, life expectancy at birth dropped from sixty-one years in 1990 to forty-three year in 2003 (Gomo, Jokomo and Mate 2003, 2,8). This has declined even further, with the World Health Organization stating in its annual report for 2006 that Zimbabwean women now have the shortest average life expectancy in the world at thirty-four years (compared with Zimbabwean males at thirty-seven). Although the WHO attributes this solely to HIV/AIDS, Zimbabwean doctors indicate that the failed health system has meant that many more women are dying during pregnancy and during and after childbirth (“Zimbabwe Women Live Shortest Lives”). While the government claims some successes (in 2008 UNAIDS reported a decline in HIV prevalence in pregnant women attending antenatal clinics — from twenty-six percent in 2002 to eighteen percent in 2006 — and a review of the epidemiological data by UNAIDS in 2005 indicated that the national HIV prevalence rate dropped between 2000 and 2004 [IRIN, 2007]), the continuing social costs of admitting HIV/AIDS status and political pressures to appear to be successfully challenging the disease would suggest that these reports have to be treated carefully. In fact, the 2010 UNAIDS Global Report stated that an estimated 1.2 million Zimbabweans are living with HIV/AIDS, a figure that no doubt misses many persons who are determined to hide, or who are unaware of, their HIV/AIDS status.

In Bulawayo, the country's second largest city (population close to one million) and the site of this research, by the year 2000, the overall death rate of 13.7 (per thousand population) had more than doubled in one decade, and HIV-related diseases were the leading cause of death in all age groups from one to sixty-four years (Bulawayo 2000, 2-3, 8-9). Between 1995 and 2001, life expectancy in Bulawayo dropped more than a decade from 52.4 to 41.2 years (Gomo, Jokomo and Mate 2003, 27-28).

Access to professional medical care and antiretroviral treatment has been a major concern in Bulawayo, as it is throughout the rest of Zimbabwe. Although access to antiretroviral treatment is a major concern throughout the entire region of Eastern and Southern Africa, the problem is worse in Zimbabwe. In Botswana, at least one third of those who need ARTs are receiving the drugs, while in Zimbabwe, Lesotho, Mozambique, Tanzania and Ethiopia,

ninety percent or higher of those in need of ART were not receiving any (UNAIDS 2005). In Zimbabwe, access to medical services and antiretroviral treatment has been worsened by a severe economic and political crisis. The economy has been characterized by massive job retrenchments, widespread unemployment, and sudden, steep increases in prices, food and basic commodity shortages. As a result, increasing numbers of households cannot meet their minimal basic needs (Grant 2003). In July 2008, Zimbabwe's annual inflation rate reached 231 million percent and by January 2009, inflation had reached 6.5 quindicillion novemdecillion percent and the economy was officially dollarized. Moreover, the weakened economy has undermined the government's ability to respond to the AIDS crisis, leaving many without medical treatment or antiretroviral treatment.

The Zimbabwean situation has been further exacerbated by the Government-instituted operation called Operation Restore Order (Operation Murambatsvina), a major nationwide demolition and eviction program that began in Harare and spread to all other urban centres in May 2005. With the demolition of thousands of homes, business premises and vending sites, it is estimated that 700 000 people lost either their homes, or their livelihoods, or both, which indirectly affected another 2.4 million people. Operation Murambatsvina has disproportionately affected the poor and disadvantaged, who have sunk deeper into poverty and are therefore more vulnerable. Many of the sick, including those with HIV and AIDS, no longer have access to health care. There is major concern that this increased vulnerability and population mobility, including spousal separation and livelihood insecurity, could have a negative effect on managing the HIV/AIDS epidemic (Tibaijuka 2005).

The health sector thus is beset by reduced maintenance of health facilities, shortages of essential drugs and equipment, high rates of staff attrition and user pay schemes that make health services unattainable for most of the poor and even many of the middle class (Grant and Palmiere 2003, 216). In the midst of such desperate conditions, however, we need to bear in mind that there are medical outreach and community care programs, as well as dedicated professionals who daily make a substantial difference to people living with HIV.

THE RESEARCH

This article is based on research from a study on Gendered Social Dimensions of HIV/AIDS Care in Urban and Rural Zimbabwe, with interviews conducted from January to May 2005 and a workshop held in Bulawayo in October 2005. The purpose of the research was to investigate medical and gendered social dimensions of HIV/AIDS care at household and community levels and to survey HIV/AIDS programs and involvement by NGOs, local and national government and international organizations.

Bulawayo, the urban site, has two central hospitals as well as nineteen municipal-run primary level care clinics and an infectious disease hospital. Bulawayo has three Voluntary Counselling and Testing (VCT) centres for HIV. In addition, the central hospitals and four municipal clinics provide VCT services for pregnant women and their partners who decide to participate in Prevention of Parent to Child Transmission (PPTCT) service. The Ministry of Health and Child Welfare sponsors two ART treatment sites in the city. Urban respondents were randomly selected from clinic TB registers in the three high-density suburbs of Mzilikazi, Magwegwe and Khami Road.

Tshelanyemba Government Hospital, which is also affiliated with the Salvation Army and is the rural site, is situated 150 kilometres to the south of Bulawayo in the Kezi-Matobo District of Matabeleland South Province. It has one hundred beds and offers comprehensive health services at both primary and secondary levels of care. The catchment population is estimated to be forty thousand within a forty-kilometre radius. Tshelanyemba Government Hospital is located in a remote, harsh area that ranks as the poorest and most impoverished in Zimbabwe, and income and nutrition levels are very low. The hospital supervises three rural health centres and has developed an extensive network of some four hundred community-based home carers. This network forms part of their comprehensive five component AIDS program: (1) Home Based Care for TB and HIV/AIDS patients; (2) Orphan care program; (3) People Living Positively with HIV/AIDS; (4) Peer Education program for HIV/AIDS; and (5) Counselling at the VCT centre. Altogether, the hospital has established a reputation as a valuable community resource and is seen as a trusted source for medical advice and support (Interview with Dr. Dawn Howse).

The rural urban comparison in this modest study is meant to promote cross-fertilization of knowledge, ideas and analysis of primary and secondary care programs in order to work towards developing integrated community care, policy, and praxis. A total of twenty-seven interviews were conducted, which included fifty-three patients (randomly selected through TB patient lists) and twenty-four carers, some as dyad interviews. Fourteen of the carers were urban and ten rural. The interviews sought to discover the basic biographical data of the informants and present household circumstances. They were asked how caregiving has affected their lives, livelihoods and workloads. In addition, carers were asked what they liked and disliked about being carers, as well as how it has affected the family (husbands, sons, daughters and other relatives). The carers were also questioned about support from other carers — whether they met and what this support meant for them. They were asked what kind of help would strengthen their role as carers, and whether TB and HIV/AIDS patients required different kinds of care. All questions were filtered through a gender lens that both sought to understand the roles, experiences and attitudes of women and men as well as the way caregiving is affected by societal assumptions about the roles of men and women in Zimbabwean society. The data also sought to compare urban and rural experience with an eye to different gender roles and relations in the two areas. The interview data was placed in the larger context of economic and political crisis in Zimbabwe as well as the regional and global contexts.

Research Results

GENDER AND CAREGIVING

Some general themes have emerged from the data. First, all carers were women. Thus the role of caregiving appears to be tied to the expectation that women (and girls) are the ones who take care of the household and who nurse the sick and make sure everything is going well for the family, particularly within the household. It is also striking that the carers were largely wives and mothers. To a much lesser extent, they were daughters, daughter-in-laws, sisters and grandmothers. In households where the younger generation had died, grandmothers often assumed heavy caregiving burdens. Thus certain women are more apt to be given / assigned the care-

giving role, but this clearly also depended on circumstances. This is in keeping with the Uganda findings of Kipp *et al.* who emphasized the

... enormous responsibilities and/or stresses primarily on women in a situation or society where women are already overburdened with their responsibilities for the general health of their families, for household food security, for their children's welfare and/or education, and for managing scarce resources (2007, 358).

Most of the carers interviewed accepted the notion that females should be the primary carers. Indeed, they expressed feelings of responsibility and obligation, particularly to their children, husbands and parents. This reflects the findings of Chimwanza and Watkins (2004) in southern Malawi, who found that most carers did not consider caregiving a problem because the patients were close relatives.

Some informants mentioned that care-giving was their Christian duty:

Within our African culture, mothers and daughters are close so in this case more attention is given to the ill daughter ... There is nothing one can like or dislike about being a care-giver, especially when one's daughter is ill. One takes all responsibilities irrespective of feelings (Tshelanyemba #33 C).

There is nothing I dislike but I am happy to be his care-giver since I am his wife (Tshelanyemba #14C).

I can't say I dislike what I'm doing since I've got no option. God has a say on this and he's my flesh and blood. When you are a mother it is very different because you cannot give up on your child. [This] is unlike when [the patient] is a non-relative whereby you know you have nothing to lose (Mzilikazi #7C).

However, one respondent felt her husband could share caring duties:

The mother and father share the duties [of caregiving]. If the patient is a male the father can help bathe while the mother does the washing of clothes, cooking for the patient and general cleaning in the house. If the patient is a female the mother does all the required duties (Tshelanyemba #11).

IMPACT ON HOUSEHOLD LIVELIHOODS AND INCOME

In the interviews, carers discussed at length the way caregiving at home had affected their livelihoods and incomes. The informants spoke of worries about food security, indicating that they had a difficult time spending adequate time in the fields when they had to perform caregiving for very sick patients.

The concerns of our respondents reflect widespread worries about the impact of HIV/AIDS on the agricultural sector. In HIV-affected households, there is increased risk of food insecurity and malnutrition as sick members are unable to work, income declines, expenditure on health care increases, caregiving burdens increase, and there is less time for looking after children (Piot and Pinstруп-Andersen 2002). In Zimbabwe, maize production declined by fifty-four percent (Kwaramba 1997). Families have switched to growing cassava, which is less labour intensive but also poorer nutritionally, and many households skip meals.

Informal trade for our respondents was often interrupted, particularly if it required travel and time away from home. The time absorbed by home-based caring and trips to the hospital encroached upon efforts to grow food and obtain income. The transport to the hospital was both time-consuming and expensive. Some carers spoke of losing their assets, as families sold off their valuable property bit by bit in order to survive. This is a common response strategy where families may be able to avoid destitution temporarily, but in the end they may not be able to avoid a downward spiral, especially when coping strategies are irreversible. In our study, when the family was unable to generate new income, this often led to destitution and the destruction of the family's material base.

Several factors made a considerable difference to HIV/AIDS affected households. The degree of illness of a patient made a major difference in the impact on family finances. If a patient was sick but not in need of constant care, the patient only needed someone around to ensure they were alright for most of the time and as long as there were enough people in the household, economic production could still take place. If the household had only one healthy person who was also the carer, of course, the situation was more difficult.

The financial and material condition of the family and the extended family also made a significant difference. Wealthier fami-

lies were able to rely on help from better-off relatives and, where necessary, to pay for extra help. Even only moderately well off families had more options than poorer households for both financial assistance and transfers such as food and labour. Food in particular was critical. Female carers in rural Malawi faced similar challenges, where poverty was the greatest burden and many could not provide food for their patients (Chimwaza and Watkins 2004). In her study in the Caprivi Region of Namibia, Thomas (2006) found that carers suffered physical and emotional strain from their inability to care adequately for their patients, and many ate very little or not at all when the patient was unable to eat, partly due to the time spent on caring and in some cases, the lack of available food.

Since HIV directly attacks the immune system, HIV and malnutrition work in tandem:

HIV compromises nutritional status and this in turn increases susceptibility to opportunistic infections. Malnutrition, on the other hand, exacerbates the effects of HIV by further weakening the immune system.... Clinical studies show that HIV disease progression is more rapid in individuals with compromised nutrition (Chopra 2003, 14).

Thus, households which are able to access nutritionally sound food transfers have a major advantage for the health of both active and sick household members. The general workload of the carer also made a difference, as a woman with many other duties was less able to absorb the demands of caregiving without dropping some key activities that would compromise the family's financial health and general well-being. In addition, many rural households that had grown accustomed to receiving transfers of cash from family members who had migrated to town, were severely constrained when those migrants returned home ill, and much-needed cash transfers for labour, agricultural inputs, basic commodities and school fees ceased. As informants lamented,

Everything was at a standstill, such as ploughing, sewing, selling of Freezits, because she needed all my attention ... Sizi¹ used to send money so as to hire some people to help me but due to her illness everything was at a standstill (Mzilikazi #9C).

This has added an extra plate on my table which has come from my little income (Magwegwe #3C).

The little that I had budgeted for the future is what we've now used. And this tells me that the future is bland for myself and the grandchildren. And we were caught unaware of this sickness. I never thought it was this bad when I was informed (Mzilikazi #9C).

It has added to my duties hence most of the time is now devoted to David and this has affected my small farming and knitting business where the sales are now reduced. Since my husband was not able to walk, I would move him from one place to another and sit beside him all day long. This was also the same during the evenings when we would nurse him [un]til morning (Tshelanyemba #4C).

Since Catherine was the breadwinner after the other daughter we no longer get basic commodities that we used to get from these daughters. Hence the children don't attend school due to hunger and failure to pay fees (Tshelanyemba # 33).

IMPACT ON CARERS' LIVES: ATTITUDES TOWARDS CAREGIVING

The interviews suggest that caregiving with all its burdens is most readily acceptable when children, husbands or parents were the patients. Thus there seems to be some unacknowledged assumption about who owes caregiving to whom, although the assumption that the caregivers would be female remained constant. The closer the tie, by blood, the more acceptable the caregiving role. However, carers did not just easily accept their responsibility for all family members. There was considerable ambivalence towards caring for husbands (or others) who had abandoned the family in the past. As one carer noted:

I felt very hurt and still am due to the fact that when my husband was able-bodied, he never used to look after his family. He would earn his money and spend it on his own, but now I feel cheated. Because now I am the one who is now pumping money out of my own pocket to better his own health (Tshelanyemba #4C).

It bothers me because Mr. Moyo had deserted me for years and I only saw him when he was ill (Tshelanyemba #1C).

Very difficult patients were often sources of resentment and comment. Some patients were very ill and the constant demands of changing bedding, washing and getting and giving medicine were clearly seen as a heavy burden. Others were difficult and demanding personalities:

Sometimes the demands of a patient would be more demanding and they can be very rough and argumentative — all of these can lower your spirits in terms of caregiving but you only need to soldier on (Magwegwe #10C).

Our findings reflect some aspects of the Caprivi Region research (Thomas 2006) where over time, caring was seen as a burden which undermined not only the household asset base but also intra-household relations, leading to ill feelings and tensions between carer and patient. These were based on mood changes of patient and carer, and were linked to the patient's health status.

While all of our informants accepted the assumption that women should be the primary carers, a number of informants found the role more onerous and disagreeable if there was no support from family, neighbours and friends. This support could be financial, but it also could involve offers of food or release time for the major carer. The evidence suggests that carers from the poorest families were often the most unhappy:

My mind was never relaxed. I was stressed and the most thing that troubled me was that he was no longer working and I had to take care of everything such as buying of food (Magwegwe #3C).

It has affected me in a lot of ways. When he was a healthy person, I never ran out of basic commodities such as soap (Tshelanyemba #14C).

But emotional support was equally important and was not always forthcoming. One informant complained:

People from the outside talk bad things ... they would phone my husband's relatives and say that I ill-treat him and don't give him food (Mzilikazi #4C).

Thus, feeling unappreciated was a heavy burden for carers, along with the problems associated with lack of financial support or relief time. It seems that lack of support or criticism from family members was more resented and hurtful than the same from

friends or neighbours. In their study on the Family Caregiver Burden in rural Uganda, Kipp *et al.* (2007) reported that the majority of family caregivers were at risk for ill health, but were already experiencing some health problems due to their high caregiver burden.

POSITIVE IMPACTS OF CAREGIVING

However, there are some positive aspects to caregiving. Some informants expressed a growing sense of self-reliance and capability. They had an increased belief in the power of prayer and a strong pride in their ability to be a carer. There were many comments that demonstrated a sense of strength that arose from successfully dealing with the burdens of caregiving and a belief in one's pivotal role in the family and community due to carrying caregiving burdens in a time of crisis. The following quotations give some sense of these feelings:

It has brought me closer to God. I had faith but now my faith is more because I saw a miracle. On everything that I used to do everything went to a standstill, but with faith her [the patient's] brothers bought food for her, on which she never ran out of food (Mzilikazi #9C).

It gives us the opportunity to show love to patients since we will be very close to them every time (Tshelanyemba # 15C).

The increased sense of empowerment and ability for these hard-working women is illustrated in the following comments:

It [caregiving] has taught me a lot of things — like bathing the sick and washing. All this has taught me to be a responsible someone.

I am now a well-known person in the society ... every [caregiver support] meeting that I attend I am given the opportunity to teach people on TB and AIDS topics. I used to be a very shy person, but since I have been a caregiver, I can teach people a lot on all these issues (Tshelanyemba #23C).

In addition, carers generally felt that the care they provided at home was much superior to that of hospitals:

You can look after the patient the way you feel they would be comfortable with. Since the patient is at home, I can take care

of his needs in time. Secondly, there are no transport expenses (Magwegwe #3).

The patient gets all he needs at any given time unlike in hospital where requests can be delayed (Tshelanyemba #11).

There is bonding and proper love is shown to the ill person. [There is] no time limit for visiting the ill person. (Tshelanyemba # 33).

THE IMPACT OF CAREGIVING ON AFFECTED HOUSEHOLDS

There are many negative effects on households that arise from the burdens of home-based caregiving for HIV/AIDS and TB patients. The workload in households with sick patients has increased significantly more for women than men in the household. Caregiving often increases the poverty of households. The strains from caregiving burdens can increase tensions and lead to quarrels. Ambivalence about caring for previously uncared for fathers or other relatives sometimes split families and caused resentment. As one carer stated,

They [the children of the patient] were heartbroken because their father never used to support them. They ... asked me: "Mama, how come you are now using your own money on Dad's medication when he himself never supported us, why?" (Tshelanyemba #4C).

The school work of children in the household is often affected negatively:

At school I went to inform them on the illness that was at home; the children's grades [were] becoming very bad due to their mother's illness (Mzilikazi #9C).

This has also affected the children and it's disturbing their education. At one time his son was insulted by one of the classmates at school and ... this has caused him a great disturbance to his education (Mzilikazi #7C).

Older women often bear an unexpected burden as the younger generation dies, leaving them with orphans to look after as well as sick patients:

It has affected my grandmother a lot since she now is looking

after a lot of orphans [my sister's sons] (Mzilikazi #4C). However, households experienced some benefits as well. Some families reported being brought together, that the family members reacted to the stress of caregiving by increasing their co-operation and help. Family burdens were more often carried by the family rather than by the women alone. One carer reported:

His [the patient's] younger brother did the laundry once in a while; when they got money they would buy Gift cool drinks and fruit (Mzilikazi #13C).

A number of informants reported increased faith in God in the family. Praying was a source of reassurance and a means of bringing families together during hard times. As one informant reported, "since Sizi's illness we would pray together with my husband" (Mzilikazi #9C). Another noticed:

Tommy's illness negatively affected my grandsons. I picked this up when they would group to pray for him (Tshelanyemba #11C).

One informant said: "I used to pray a lot and I know that is where I got all the strength to overcome all these problems" (Mzilikazi #9C). Faith also helped people deal with great personal loss:

I took it as the Almighty came to take his child — he gives and he takes. I used to give them the little that I had (Mzilikazi #21C).

PROBLEMS AROUND CAREGIVING AND POSSIBLE SOLUTIONS

Home-based carers reported the following problems. Finances were the most serious issue, and were mentioned by almost all urban and rural informants. Food was a problem for many, especially the poorest.

I never had enough money to buy food; we would go for days without food. Sometimes I would cook veggies without oil and we [would] sleep on that (Magwegwe #3C).

One has to look for a special diet for the patient (Tshelanyemba #20C).

Some caregivers also expressed frustration at their lack of knowledge about caregiving. And to make matters worse, they had difficulty finding and affording protective items. Many carers reported caring for patients without gloves or any sterile equipment at great

danger to themselves. As one informant said, "I ended up giving care without protecting myself" (Mzilikazi #21C).

The problem of transportation to the hospital to see the doctor and receive medicine (something that some patients had to do every day) was costly and often dangerous. Patients and their caregivers were in danger of being robbed by thieves on the way. Solutions came in a number of forms. The most appreciated and probably most common source of help came from family members. As one informant reported, "We all put our heads as one — when one has the money we do manage on buying this and that" (Mzilikazi #13C). Another reported: "My other daughter ... moved in with us last week to give a hand in looking after her brother" (Mzilikazi #22C). Our findings are similar to a rural Malawi study, where for most carers, kin and community members provided social, moral and physical support and some modest financial support (Chimwaza and Watkins 2004).

Some informants stated that they returned to economic activities — there was simply no other way to survive. Sometimes patients were left on their own for a time as family members returned to farming or work/business to earn money. People cobbled together support each day so they could manage to find some money and produce some food. Some carers decided not to go with the patient to the clinic to avoid robberies and to carve out some time for economic and other crucial activities.

Some caregivers decided that they would simply keep going despite family and community criticism. As one woman reported, "I ignored all the rumour mongers and my in-laws were very understanding of the situation I was in" (Mzilikazi #4). Support from the family helped this woman to deal with the difficulties of lack of support from the community.

Support from other carers was also important. Twenty-six percent of the carers in the urban area reported talking regularly with other carers, while eighty percent of rural respondents did so. This may reflect the support system in place for carers in the rural areas, which was very much strengthened by the support of the local mission hospital as well as strong community ties. The urban respondents seemed to make less use of caregiving support groups, which may reflect either the wider community networks of the city or the greater anomie of city life. This needs much more investigation.

Those who regularly met with other carers were very positive about using social networks for emotional support and advice about caregiving. They reported getting advice on how to care for the sick, especially in regard to hygiene and giving medicine. The carers also learned more about the psychological aspects of caregiving. As one informant recalled, “[we learned] that when you are a caregiver you should show love and not isolate the ill because this may affect them very much” (Tshelanyemba #14C). The groups offered information on how to avoid spreading the disease, although one woman warned: “They [the groups] are very helpful but we haven’t come up with a solution yet on how our children can keep away from this deadly disease” (Tshelanyemba #11C).

The groups provided each other with hope and courage and offered a forum for problem-sharing and mutual support. Both the emotional support and the practical advice on methods of caring were very appreciated. The groups also helped women to discover and develop leadership skills, and some women developed leadership skills and powers that they had never known they had. These skills provided the basis for taking on more significant roles in community efforts to combat the disease.

While the medical facilities were regarded as crucial, especially in the distribution of medicines and equipment, many informants expressed considerable frustration with the medical facilities and personnel, particularly in Bulawayo. The carers wanted more follow up with patients and more home visits. They claimed the poor suffered particularly:

What is it that the hospitals have given us to help with the sick with the home-based care? They do not follow up on their patients, no equipment to use, what has gone wrong in hospitals, we no longer understand? (Mzilikazi#21C).

The poor die and the richer ... live since they can afford everything.... Better medication, accommodations and care in the hospitals (Mzilikazi#4C).

Conclusion

This study raises a number of issues. Clearly most respondents, whether rural or urban, favoured home-based care, which was seen as more supportive, more effective and more personal and flexible.

Close monitoring might be better in a hospital, but the hospitals did not provide the love needed by patients. But the carers did worry about their lack of training, skills, equipment and medicine at home. They would like to have doctors and nurses visit patients at home. They need medical aid kits and government help with obtaining necessary supplies.

Those who attended support groups found them very important, although this was more a rural than an urban phenomenon. The carers we spoke to wanted more support for those groups. They also want relatives to help out more.

From a human security perspective, women and girls place themselves in vulnerable positions by providing care without proper protection. They also endanger their physical and emotional health, not only through heavy physical work associated with caregiving, but also through the emotional stress of worrying about scarce resources, missing work and farming, the inability to provide adequate food and nutrition, and attempting to meet the basic needs of the household, especially when the sole breadwinner was critically ill. Added to this is the strain of being a witness to the long, slow and often painful demise of husbands, daughters and sons. The difficulty of these deaths is often further exacerbated by the resultant introduction of orphans into the household at a time when the household has often used almost all scarce resources for caring and for funerals, and when the carer is physically and emotionally exhausted from the ordeal of caring for one or more adults.

From a gendered perspective, the study raises a number of important issues. First, while females are still largely seen as the "natural" carers for HIV/AIDS patients, many informants insisted that all members of the family should get involved. In some circumstances, men and boys in the family had become more actively involved in home-based caregiving. Their adoption of a more nurturing role provided an alternative to gendered assumptions that place the burden of care squarely on women and girls. Moreover, many carers reported gaining a sense of competence, experience with decision-making and a belief in one's ability that provide both self-esteem and leadership skills. These developments strengthen women's capacity and authority and can challenge stereotypes that place women solely in the private arena as

dependents of men. They raise the possibility that women who acquire leadership skills and competences can use these skills in ways that lead to new and important roles for women in the fight against AIDS and in society in general. Thus the burdens of home-based caregiving on women in Bulawayo and Tshelanyemba suggests that gender assumptions and practices may be shifting under the pressure of the HIV/AIDS pandemic — both for widening the concept of caregiving (which is now starting to be done by men and boys as well as women and girls) and for expanding the gendered notions of competence by offering women who have demonstrated capabilities as caregivers the ability to take on wider roles in the public and domestic arenas.

At the same time, it is important to recognise that many women and girls are exhausted not only by the extent of their efforts as carers, but also by the general lack of support in the form of training, equipment and personal hygiene products. Their duties have expanded exponentially within the pandemic, and the demand caregiving places on their energies has diminished their capacity to earn money, to work in the fields, and to somehow provide food for their families, especially the special food required by TB and HIV/AIDS patients. This is especially problematic as breadwinners become sick and die and as the numbers of dependents grow with the fostering of orphans. Spiritual and psychological support is also a necessity as stress increases and as hardworking mothers, sisters, aunts, daughters and grandmothers tend to the sick and dying. While families may be drawing closer, the burden of care and nurturing still tends to fall largely on exhausted females. Thus, the possibilities for widening gendered conceptions of caregiving and bringing males into the process, as well as the empowerment of carers, are important steps towards establishing more equitable gender relations and practices as well as necessary conditions for spreading the burden of HIV/AIDS care in Zimbabwe (and the world).

Note

¹ All names have been changed to protect the identity and privacy of respondents.

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